Religious, Medical, Ethical and Legal Perspectives on End of Life Issues

Nov. 10, 2014
Conference Summary

AN INTERPROFESSIONAL CONTINUING EDUCATION ACTIVITY

Presented by the Institute for Jewish Continuity; the University of Maryland Schools of Medicine, Nursing, Pharmacy, and Social Work; and the Maryland Healthcare Ethics Committee Network at Maryland Carey Law
Introduction

For most of human history, dying once one became seriously ill or injured was brief and death came quickly. If a person was fortunate, there may have been just enough time for spiritual advisors, family members, and other loved ones to gather around and extend their final farewells. Today, due to remarkable advances in medical care, patients with serious illness often experience prolonged deaths. The dying process can extend over months and in some cases years, providing patients and families with time to reflect on life, contemplate death, and consider options for end-of-life care.

But we live in a death-denying culture. Rather than thinking and talking about death, most of us do what we can to avoid such thoughts and discussions and focus on the time that remains. Inevitably, our efforts to avoid talking about death extract a tremendous toll — on the dying person, who is left to deal with his or her fears and unspoken worries alone; on families and other loved ones, who miss the opportunity to express their love and forgiveness and say good-by; and on care professionals, who struggle to identify and address the person's end-of-life preferences and needs in the last hours and days of the person's life.

Among professionals who work with the dying, there is growing concern about the quality of care at the end of life, as well as a growing interest in improving end-of-life care. The concern and interest are framed by the recognition that end-of-life care does not belong to a single discipline or profession, but is best when provided by an interprofessional team whose members collaborate to meet the physical, emotional, and spiritual needs of dying patients and their families.

This interprofessional view of end-of-life care served as the basis for the conference, Religious, Medical, Ethical, and Legal Perspectives on End of Life Issues, which was held at the University of Maryland, Baltimore, on November 10, 2014. The conference was attended by more than 100 professionals from medicine, nursing, pharmacy, social work, and law, as well as religious leaders and interested laypersons, and provided an interprofessional forum for examining issues and exchanging ideas, perspectives, and practices pertaining to end-of-life care.

This report summarizes insights and strategies shared by conference presenters and attendees. It is our hope that the report is useful to individuals and groups that are similarly committed to improving the end-of-life care and support provided to patients and families served by our health care system.

Conference Structure and Objectives

The one-day conference was guided by the following objectives:

- Identify religious and ethical questions that arise in the care of patients at the end of life
- Discuss strategies to help patients, family members, and health care providers navigate the complexities of end-of-life decision making
- Apply strategies to address differing interpretations of religious and ethical obligations toward the dying patient
- Demonstrate how to respect patients’ and families’ religious values and beliefs when providing end-of-life care

The conference was structured to facilitate the presentation and discussion of diverse perspectives and to encourage the participation of audience members. In opening remarks, Steven Czinn, MD, and Rabbi Shmuel Silber set the stage for conference participants by highlighting some of the complex issues that arise for patients, families, and health care providers at the end of life, and noting the benefits to patients and families of an interprofessional approach to end-of-life care.
The opening remarks were followed by three panel discussions. The first two panels focused on case studies — the first involving an adult woman with lymphoma, the second involving a child with advanced neuroblastoma — in which the patient, family, and health care providers grappled with a range of complex issues and decisions. The panelists included representatives from medicine, nursing, pharmacy, social work, and law. In responding to the case studies, the panelists drew on their professional expertise and experiences to identify strategies for helping patients and families anticipate and address issues that often arise during the dying process. The third panel examined religious perspectives on death and dying. The panelists, representing the Christian, Jewish, and Muslim faiths, offered insights and information about religious beliefs and traditions that may inform patient preferences and that can be a source of hope and solace to dying patients and their loved ones.

Case Studies: End-of-Life Issues and Strategies for Care

The adult case study involved a 35-year-old woman who was diagnosed with a high-grade, rapidly growing lymphoma. The patient received aggressive treatment that included systemic chemotherapy, injections of chemotherapy into her spinal fluid, and an allogeneic (donor) stem cell transplant. Despite periods of remission, the cancer continued to advance. Following the stem cell transplant, the patient developed a serious immune system reaction called “graft versus host disease,” and experienced profound neurological deficits with partial paralysis and an inability to communicate verbally. The patient's husband was a constant presence at her bedside, and as her condition worsened he served as her surrogate decision maker. For a period of time, he was unable to accept any limitations on his wife's medical care and advocated for new and continued treatments while rejecting the care team's suggestions to shift the focus of his wife's care to comfort and support during the dying process. As his wife became more neurologically impaired, the husband reluctantly agreed to a do-not-attempt resuscitation (DNAR) order. The patient died a short time later.

The child case study involved a young girl who was diagnosed at three years of age with advanced stage IV neuroblastoma with malignant cells in her bone and bone marrow. The patient received aggressive treatment, including systemic chemotherapy, surgery to remove the tumor, a stem cell transplant, and radiation therapy. She experienced a period of remission following the stem cell transplant, and again following experimental therapies, but the cancer ultimately recurred in her bone and bone marrow. After seven years of treatment, the child indicated she had enough and wanted treatment to end. Initially, her mother could not bring herself to sign a DNAR order, noting that it felt like she was giving up on her child. The care team referred the patient and family to palliative care. Radiation therapy was administered to treat painful bone lesions and the patient received help fulfilling last wishes. A short time later, the patient died at home, supported by hospice and surrounded by her family.

In commenting on the case studies, the panelists offered insights and suggestions for end-of-life care related to the following themes: Initiating discussions about end-of-life care; Involving palliative care; Balancing hope and reality; Supporting decision making by patients and surrogates; and Remaining present.

Initiating Discussions about End-of-Life Care

— Panel members emphasized the importance of beginning conversations aimed at understanding patients’ values and belief systems early in the course of a serious illness, instead of waiting until the illness has progressed and treatment options are exhausted. For example, while laying out the treatment plan, providers can begin asking the patient and family about their expectations, hopes, and desires for treatment and resources for coping, and also inquire
about preferred surrogate decision makers or individuals who will make decisions if the patient is unable. The panelists suggested that providers also use these early conversations to discuss the principles that guide their practice, including their commitment to doing all they possibly can to treat the disease in accordance with the patient's goals and as long as the patient has a good quality of life and reasonable chance of survival; as well as their commitment to being honest with the patient and family about the patient's clinical situation and prognosis, and to informing patients and families when it is appropriate to shift from interventions that no longer improve or sustain living, to interventions that maximize comfort and support. Such conversations foster the development of patient-provider relationships that are based on mutual trust and understanding and provide a foundation for future discussions about the goals of care throughout the illness trajectory and for discussions and decision making about end-of-life care.

Involving Palliative Care — A key recommendation offered by the panelists was to introduce palliative care early in the course of treatment. Too often, providers propose palliative care after telling patients, “There is nothing more we can do,” thus sending the message that they are giving up on the patient and casting palliative care as something that is to be feared, and that is useful only to the dying. By incorporating palliative care into the treatment process at an early stage, patients and families come to view the palliative care team as partners in care and as valued resources when the goal of care shifts from aggressive treatment to aggressive comfort. Palliative care providers are uniquely focused on tailoring treatment to benefit a patient's comfort. In the early stages of an illness, this might involve gaining control over symptoms. In the later stages, palliative care providers can provide further interventions to ensure a patient's comfort, and support patients and families in identifying and resolving concerns and issues that may surface at the end of life. Through these and other services, palliative care not only helps the dying patient, but also eliminates the toll a mishandled death can take on survivors in the form of negative mental health consequences and diminished human flourishing.1 Indeed, panelists noted, rather than viewed as “doing nothing,” palliative care should be recognized and embraced as a critical element of the care process.

Balancing Hope and Reality — Hope is a source of sustenance and strength for patients and families, and maintaining it is important at every stage of treatment. However, equally important, noted the panelists, is balancing hope with reality. Helping patients and families understand the nature of their clinical situation empowers them to make more informed treatment choices and to arrive at decisions that are consistent with the patient's values, beliefs, and best interests. The panelists suggested that in speaking with patients and families, providers try to clarify what patients (or their surrogate decision makers) are hoping for. In the early stages of treatment, most patients and families hope for survival. At later stages, hopes may vary, with some patients and families hoping for a treatment that offers a reasonable possibility of remission, others hoping for minimal pain and side effects, and still others hoping for a chance...

“Maintaining a balance between hope and reality is important throughout the treatment process. This requires having different discussions at different stages of an illness. In the initial stages it involves focusing on the hopeful side while also introducing and acknowledging the fact that some people die. Ongoing communication is key.” - Henry Brem, MD
to achieve a long-cherished goal or experience a peaceful death. By discovering the nature of the hope, providers might find that they are able to help patients and families achieve their hopes at different points in the course of treatment.

**Supporting Decision Making by Patients and Surrogates** — For many patients and families, end-of-life decisions are fraught with uncertainty and weighted by sadness and grief. As illustrated by the case studies, some of the most difficult decisions involve whether to pursue a new treatment after many others have failed, and whether to suspend further life-prolonging treatment or rescue interventions (e.g. cardio-pulmonary resuscitation) and pursue comfort measures only.

Ideally, adult patients are able to serve as their own decision makers. However, if an adult patient has physical or cognitive limitations that preclude this, the decision-making role is assumed by the patient’s spouse or another surrogate. For children, parents are usually the designated decision maker by law. (There are some exceptions to this rule, which vary by situation and by state. It may be necessary to involve legal counsel in assessing these situations.) While treatment decisions must ultimately be made by the patient or patient’s surrogate, providers can help with the decision-making process by providing information that helps the patient or surrogate assess the benefits and burdens of available options and arrive at a decision that is consistent with the patient’s values.

Decision making can be especially difficult for surrogate decision makers who are uncertain of the patient’s preferences regarding treatment. Advance directives prepared by the patient and outlining the patient’s wishes are critically important resources for surrogate decision makers. In the absence of such directives or when there is still some uncertainty, providers can help surrogates with decision making by identifying questions for them to consider, such as whether the patient ever expressed a preference in relation to a similar situation; whether the patient has religious or moral beliefs or personal values that shed light on his or her preferences; and whether the patient has ever shared concerns about the impact of the illness on his or her family, children, or friends. Surrogates who are still uncertain how to decide can consider what the proposed treatment might mean for the patient’s prognosis, how much physical pain or discomfort it might entail, and whether it is likely to significantly impact the patient’s dignity by subjecting the patient to humiliation or dependency and how the patient would feel about being so vulnerable. (These and other suggestions for health care surrogates are discussed in the Maryland Health Care Decisions Act, Section 5-601.)

While children are not in a position to make final decisions about their care, panelists encouraged providers to have parents discuss decisions with their child and learn about the child’s preferences and concerns. The panelists observed that even very young children often have a good understanding of their situation, and frequently have opinions, desires, and preferences that may have a bearing on how parents weigh treatment options. Additionally, providers have an ethical obligation to incorporate children’s perspectives into treatment decisions, an obligation that becomes stronger the closer children are to being of an age or status in which they are able to make decisions on their own.

**Remaining Present** — Staying emotionally present for patients and families as they struggle with uncertainty is a daunting challenge for many health care providers. It can be especially difficult for providers who straddle the realms of clinical care and research and are eager to test out promising new
treatments, and for providers who disagree with a patient's or family's choices. Rather than pulling back from patients and families, panelists urged providers to keep the lines of communication open by accepting a patient's and family's emotions and reactions, offering support rather than judgment, and providing information to help patients and families carefully weigh their options and decisions. Panelists also cautioned providers to be mindful of their own personal biases, preferences, and beliefs and how these might impact their reactions to patients and families with whom they disagree, and urged providers to recognize the importance of self-care in sustaining their own well-being and capacity for care.

Religious Perspectives on Dying and the End of Life

For a great many people, religious beliefs and practices are central to their way of being, and provide guidance for living and hope and comfort when dying. In the third panel presentation, clergy from the Christian, Muslim, and Jewish faiths shared spiritual and religious perspectives on the illness and dying experience and explored ways in which religious beliefs and practices can inform and enhance care at the end of life.

The panelists began by noting the deep reverence for life and respect for death that is shared by their faith traditions. For Christians, this perspective is expressed by Jesus's emphasis on healing, which offers Christians hope in the face of serious illness, and the story of his death and resurrection, which offers solace when death appears inevitable. Followers of the Islamic faith similarly view the body as a sacred trust from God and place great value on preserving life and restoring health; however, Muslims also believe the quality of a person's life is as important as the lifespan and consider death an inevitable part of the human journey. In the Jewish tradition, respect for life is reflected in the saying, “If you sustain one life it is as if you sustain an entire world.” At the same time, Judaism teaches that death is an integral and necessary part of human life and has meaning as part of God’s plan.

Beyond offering patients and families a perspective on life and death, the different faiths offer their followers a connection to a higher power that is both benevolent and merciful. The panelists noted that this spiritual connection is strengthened through prayer and can be a source of great hope and comfort for patients and families confronting the end of life. The panelists also described other practices that hold special meaning at the end of life. Prominent among these is visiting the sick and suffering. Greatly valued by each faith, visits from members of the faith community assure patients and families of companionship as well as reassurance that they have not been forgotten and are not alone in their suffering. Other practices focus on easing the dying process and preparing the person for the journey ahead. For example, in the Islamic tradition the Koran is recited in the dying person's presence. The Koran is also recited at a person's birth and thus heralds the beginning and the end of the human journey. In the Jewish faith, the dying are offered an opportunity to apologize for any hurts they may have inflicted on others, and to ask for and grant forgiveness. Also in the Jewish tradition, after a person dies, someone stays with the body at all times, reflecting the belief that the soul remains near the body until burial and should not be left alone.

Many patients and families seek reassurance and guidance from religious leaders when making end-of-life decisions. The panelists noted that when working with patients and families, they are guided by the focus on healing and comfort that is part of the patient's and family's faith tradition,
and strive to help patients balance hope with reality and find guidance in their religious beliefs when considering different options. Above all, said the panelists, they seek to reassure patients and families that they will not be abandoned in their time of uncertainty and suffering.

The panelists closed by urging health care providers to learn about their patients’ spiritual beliefs and practices and incorporate them into the plan of care whenever possible. In doing so, providers will help patients and families address some of life’s greatest challenges — finding hope in the midst of despair, comfort in the face of suffering, and meaning in dying and death.

Conclusion

Throughout the conference, panelists drew on their experiences working with patients and families to offer insights and suggestions for improving end-of-life care. (See the sidebar for a summary of panelists’ suggestions.) Underlying each panelist’s comments was a deep appreciation for the value and importance of a team approach to care, one in which providers and professionals from medicine, nursing, pharmacy, social work, spiritual care, and other disciplines work together to meet the unique needs of patients and families and help them address challenges they may encounter at the end of life. This overarching theme of interprofessional collaboration was perhaps best captured by Rabbi Silber through his observation that, “We cannot conquer death, but if we collaborate, if we work hand-in-hand, respectful of each other’s beliefs and sensitivities, we can make death and the transition from this world and this life just a bit easier.”

“By supporting patients and families through the dying process, palliative care helps eliminate the toll a mishandled death can take on survivors in the form of negative mental health consequences and diminished human flourishing.”

- ANITA J. TARJIAN, PhD, RN

Toward Improving End-of-Life Care: Strategies for Providers

- **Initiate end-of-life discussions early and continue them throughout treatment:**
  Beginning with the initial diagnosis, take time to learn about the patient’s values and beliefs. Also discuss the principles that guide your practice, including your commitment to providing the best possible treatment at all times and to being consistently honest with the patient and family so that they can – as much as possible – participate in shaping the goals for treatment, including end of life care.

- **Involve palliative care:** With a focus on assuring comfort, palliative care providers offer a valuable perspective at each step of the treatment process. When the goal of care shifts from aggressive treatment to aggressive comfort, palliative care helps not only the dying patient, but also survivors. By helping the patient’s loved ones make arrangements for the patient’s care, supporting them in saying good-by and addressing other unresolved issues, palliative care helps to eliminate the toll a mishandled death can take on survivors.

- **Balance hope and reality:** Maintaining hope is important at each stage of treatment; however, equally important is balancing hope with reality. By helping patients understand the nature of their clinical situation, providers empower patients to make more informed decisions. Similarly, by learning what patients and families are truly hoping for, providers may be able to help patients and families achieve cherished hopes at different points in the course of treatment.
• **Support decision making by patients and surrogates:** Ideally, patients are able to participate in decisions about their own care; however, in some cases, a surrogate decision maker may need to serve on the patient’s behalf. Advance directives, in which patients spell out their wishes for end-of-life care and treatment, provide important guidance to surrogate decision makers. Providers can offer further support for decision making by helping patients and families consider what the proposed treatment might mean for the patient’s prognosis, how much physical pain or discomfort it might entail, and whether it is likely to significantly impact the patient’s dignity by subjecting the patient to humiliation or dependency and how the patient might feel about being so vulnerable.

• **Incorporate religious and spiritual perspectives into the plan of care:** Spiritual beliefs and practices are central to many patients’ lives and can be a source of hope and comfort during serious illness and at the end of life. Faith leaders (e.g. clergy, clerics) can support patients in balancing hope with reality, help patients find guidance in their religious beliefs as they consider different options, and reassure patients that they will not be abandoned in their time of uncertainty and suffering.

## Appendices

Appendix A. 2014 Conference Agenda
Appendix B. 2014 Program Planning Committee & Faculty

## Acknowledgement

The Planning Committee appreciates the support for publication of these proceedings provided by the University of Maryland, Baltimore’s, Center for Interprofessional Education, and writing and editing support provided by Beth Kantz of Corrigan Kantz Consulting.
Appendix A.
2014 Conference Agenda

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<th>Time</th>
<th>Session</th>
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<tr>
<td>8:30 – 9:00A</td>
<td>Registration and Continental Breakfast</td>
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<td>9:00 – 9:15A</td>
<td>Welcome &amp; Program Overview</td>
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<td>Steven Czinn, M.D.</td>
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<td>9:15 – 9:45A</td>
<td>Healing with Dignity: Enhancing Care at the End of Life through Mutual Understanding</td>
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<td>Rabbi Shmuel Silber</td>
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<td>9:45 – 10:00A</td>
<td>Overview of Case Study in an Adult</td>
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<td>Aaron Rapoport, M.D.</td>
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<td>10A – 10:50A</td>
<td>Inter-Professional Responses – A Panel Discussion</td>
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<td>John G. Cagle, PhD, MSW, UMB School of Social Work</td>
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<td>Henry Brem, M.D., Johns Hopkins School of Medicine</td>
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<td>Diane E. Hoffmann, JD, MS, UM Carey School of Law</td>
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<td>Mary Lynn McPherson, PharmD, BCPS, CPE, UMB School of Pharmacy</td>
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<td>Anita J. Tarzian, PhD, RN, UMB School of Nursing</td>
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<td>10:50 – 11:00A</td>
<td>Q&amp;A</td>
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<td>11:00 – 11:15A</td>
<td>BREAK</td>
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<td>11:15 – 11:30A</td>
<td>Overview of Case Study in a Child</td>
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<td>Teresa A York M.D.</td>
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<td>11:30A – 12:20P</td>
<td>Inter-Professional Responses – A Panel Discussion</td>
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<td>John G. Cagle, PhD, MSW, UMB School of Social Work</td>
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<td>Anita J. Tarzian, PhD, RN, UMB School of Nursing</td>
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<td>12:20 – 12:30P</td>
<td>Q&amp;A</td>
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<td>12:30 – 1:30P</td>
<td>LUNCH</td>
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<td>Assigned Inter-Professional Tables for Case Discussion</td>
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<td>1:30-2:30P</td>
<td>Religious Perspectives on “God’s Will” – A Panel Discussion</td>
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<td>David Harness – A Christian Perspective</td>
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<td>Tahara Akmal – A Muslim Perspective</td>
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<td>Rabbi Shmuel Silber – A Jewish Perspective</td>
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<td>2:30-3:00P</td>
<td>Open Discussion</td>
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<td>Rabbi Shmuel Silber &amp; Dr. Steven Czinn</td>
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Appendix B.
Program Planning Committee† & Faculty*

Committee Members

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